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Case conference

The thin red line

The following case was presented to an informal support group by a medical student, following the student's expressed concern that he seemed to be looking after more patients who had been harmed by their period in hospital than who had benefited. When asked to give an example, he introduced the following case of a widower crippled by coronary artery disease, who underwent an investigation which he did not understand, which was to gain experimental knowledge, and which ultimately appears to have done him serious harm. As the discussion took place in the student's own hospital, the names of the participants have been changed. The student presents the case, and the group afterwards attempt to define more clearly their misgivings.

Background

George Young was in his late fifties when I met him. He was a widower, his wife having died of breast cancer four years before, and he had lived since her death on his own in a flat in a four-storey building. He had been admitted to hospital following an episode of increasing chest pain and breathlessness, which was labelled as 'crescendo angina'. As this episode had progressed, he had found himself unable to get out of his flat, which had no lift, and his usual angina medication, *beta*-blockers and sublingual trinitrate, seemed to have little effect on the pain. When I saw him in Casualty, a proud independent man, he was clearly at the end of his tether – his immediate family lived in Australia, and as his block of flats was being modernised, some of his immediate neighbours had moved out and he had found difficulty in getting food. In spite of a local social workers' strike, the home-help service was still running, but when he had telephoned his own doctor to discuss this idea, his doctor had called and insisted he be admitted to hospital. He had not wanted to do this, and was still a little angry with his doctor when I spoke to him that first evening.

This was not his first experience of hospital, nor of chest pain. He had been a taxi driver, overweight and a smoker, and six years before had had his first heart attack. After this he had had to retire, but had a second heart attack a year later and after this had been disabled by anginal pain on climbing stairs. When his wife discovered the lump in her breast, they discussed the future openly, in particular the possibility that their roles might be reversed, and that he might find himself looking after her. They accordingly took themselves to their family doctor, and were both referred to hospital, Mrs Young for eventual mastectomy, and Mr Young for a cardiologist's opinion. The cardiologist in turn referred Mr Young to a cardiac surgeon, and after an admission and cardiac catheterisation, he was advised that he had a blockage in one of the large heart arteries, and that a new surgical technique of bypass which this surgeon was developing would help him. His wife's operation appeared to be successful, so he agreed: a cardiac bypass graft was instituted. His convalescence was physically satisfactory but saddened by the discovery that his wife had secondary spread of the tumour. In the subsequent six months she deteriorated rapidly in spite of treatment, and died. Until the last week, he had looked after her himself at home, but immediately after her death he collapsed in the street and was admitted with a third minor heart attack. His life until his latest admission he found hard to describe, but it seemed medically uneventful. However, he clearly had isolated himself more and more from his friends, and had taken to drinking quite heavily in the evenings at home in his flat. The arrival of a new grandchild in Australia had altered this, four months before his last admission, and he had begun to 'take himself in hand'. He was justifiably proud of getting on top of his bereavement, and had wanted to stay at home to continue the progress, and eventually go to Australia to see the new child.

After admission from Casualty on the day that I saw him, immediate studies showed that he had not had a further heart attack, and after bed rest and change of drug treatment, his exercise tolerance increased, although he still found stairs difficult. There seemed little possibility of an early transfer of Council accommodation, as he had been on the list a long time and frequent unsuccessful medical applications had been made. He was visited by the cardiac surgeon, who suggested that a second operation might be possible. Mr Young absolutely refused, but was persuaded to accept 'a minor procedure which could help slightly'. These were the words that he remembers the surgeon using to

describe a repeat cardiac catheterisation. I was unclear in what way a catheterisation could help Mr Young, and was informed when I asked the surgeon's registrar, that it was intended 'to check that the graft is still working, as his was a new style of operation, and we need to evaluate it as part of our research programme'.

The cardiac catheterisation was a disaster. Mr Young arrested twice in the course of the procedure, and the catheter got stuck. When it was removed the groin wound did not heal, and a femoral aneursym developed. He had calf pain at rest, and then developed a thrombosis in the artery. He was now demoralised, and refused operation until gangrene had set in. Eventually he was persuaded to accept surgery, by which time a below-knee amputation was necessary. It has been difficult to get him mobilised since then: he remains depressed and withdrawn, and apparently sees no use in getting himself onto his artificial leg. As he is below 65, perhaps luckily he is not a candidate for the geriatric ward and he remains on the medical ward. No-one appears to know quite what to do with him, and I think I share his anger for what happened. Is this reasonable?

DR BICKERSTAFF: PHYSICIAN

This sounds, tragically, not such an unusual story, and I'm not clear how it could have been avoided without knowing more technical details. The general practitioner's admission seems sensible; although Mr Young could have been kept at home, but with no-one there to look after him, it would have been a great risk, and left everyone feeling very guilty, had he come to grief between visits. But technicalities apart, I take it the focus for Mr Young's anger, and therefore perhaps for our discussion, is his cardiac catheterisation.

MRS JENKINS: MEDICAL SOCIAL WORKER

As I understand it, Mr Young gave consent to the catheterisation on the understanding that it was a therapeutic procedure, whereas the registrar's comments make it clear that it was only to reassess the previous operation, and that was for research purposes. Mr Young had refused another operation, so it could not be construed as being a preparation or exploratory investigation before another operation, as he had refused to countenance this!

DR HIDE: GENERAL PRACTITIONER

It is possible that the surgeon hoped the patient would change his mind, but events prove that Mr Young was consistent. Although we only have third hand evidence of what was said, it does seem that the explanation was inadequate, and the consent therefore must be invalid, as it is not truly informed.

MR BRUNT: SURGEON

Studies show that patients under stress do not remember what was said to them, but this still does not exonerate my colleague, as I can think of no way in which a catheterisation would actually have helped the patient. What I think may have happened is that the patient's natural gratitude for the help he was given last time by the surgeon clouded either his perception, or his judgement, or both. As an experimental surgeon, you walk on your own knife edge, you want to be fair and inform the patient, but you also don't want to scare him off, because not only are you naturally curious about the outcome of your surgery but you have your future patients' interests to consider, as you want to offer them an operation that works.

DR HAMILTON: COMMUNITY PHYSICIAN

And you have the future of your department to consider, as if it doesn't produce enough papers you won't have enough money to make *that* work! I am casting no dirt at the reputation or intentions of the surgeon in this case, but it has to be admitted that the pressure to produce papers for publication is now intense and hectic, and it takes a strong-minded team to resist them. Barber's study of experimentation in medical institutions in the USA found that the relatively unsuccessful scientist was much more likely to overlook important ethical principles in his zeal to produce work, and in this study they defined a group of 'high quality' scientists who were usually able, both hypothetically and in their own work, to make reasonable ethical decisions, and a group of 'extreme mass producers' who were unsuccessful and often unethical, and involved in a desperate paper chase. These latter investigators are often younger and less experienced but involved in work that has less well-organised supervision. Barber reached his results by using a 'risk versus benefit' rating, that is the likely risk to the patient balanced against the chances that the investigation would lead to an important medical discovery. In Mr Young's case, there are available clinical means of measuring the heart's *function*: the patency or otherwise of the graft does not necessarily influence this, and there was little chance that much useful information would be discovered.

DR HIDE

But the problem is one stage further back than that. You are saying that the benefit to science, and to future medical knowledge did not really justify the risk – although I think that is arguable. What is clear is that, benefit to science or no, Mr Young appears to have felt that the benefit would accrue to *himself*, to his own health. This is surely the crucial line that the surgeon has crossed. Mr Young does not seem to have been offering himself for scientific study, but for treatment. He was

deceived in some way, and is now irreparably bitter.

THE REV SCOTT: CHAPLAIN

I think we must remember that there is something of the experimental in every situation where a doctor is treating a patient: after all, we are dealing with an individual with an individual's responses, which can never with absolute certainty be predicted, and it would be a poor doctor who did not learn from each case he treated for the benefit of future patients. However, I think you are right that this surgeon crossed the thin red line without asking honestly to himself *cui bono?* It raises the wider issue: who are reasonable research subjects when it comes to medical research? The idea of informed consent means that, at one end, we would all agree that the researcher is entitled to experiment on himself: and on the other end of the scale, that comatose, demented or infantile people unable to make decisions are absolutely forbidden subjects. This leaves us with a type of sliding scale, balanced against the medical need for the research information, where the more important the research the more permissible it would be to approach patients poorer in motivation, understanding, and freedom of decision; and the more abstruse and abstract the study, the more vital to restrict it to those capable of completely comprehending the risks and benefits. This hard rule is actually the reverse of what appears to happen: the less ethically justifiable the research, and the more marginal the benefit, the more we find poor or 'captive' subjects being used; the classical case being the use of poor blacks for the Tuskegee study of untreated syphilis. Prisoners likewise have been abused: and I think we should consider patients (especially patients in a physical state like Mr Young) to be in a 'captive' state. The hospital is like a prison cell, and captivity is strengthened by the emotional bonds of a patient's gratitude which shackle him to his own physician.

MR BRUNT

I agree with your view, but many would feel that this ruling would lose many chances for the advancement of our knowledge in the battle against disease.

REV SCOTT

This possible loss has to be balanced against the loss to the individual and to the community of trust in the physician. Mr Young had to trust himself to his physician, as he had trusted himself to his wife. His is the rage of a man betrayed. Somehow Mr Young has to regain his trust, and his faith in himself. I think we all feel this could be the most difficult battle of his life. I think our colleague who presented the case may be the one to show him how to help himself back to trust.